



2 0 2 5
**ANNUAL
REPORT**

A year shaped by families,
driven by research, and
strengthened by community.

the power of

YOU

JAKE, AGE 19
DIAGNOSED AT AGE 2
PHOTO: T. PARMELEE PHOTOGRAPHY

A MESSAGE FROM THE CEO AND BOARD PRESIDENT

This year has reminded us that the Angelman Syndrome Foundation is not defined by a single program, discovery, or moment. It is defined by people. Families. Researchers. Clinicians. Donors. Volunteers. Advocates. Friends.

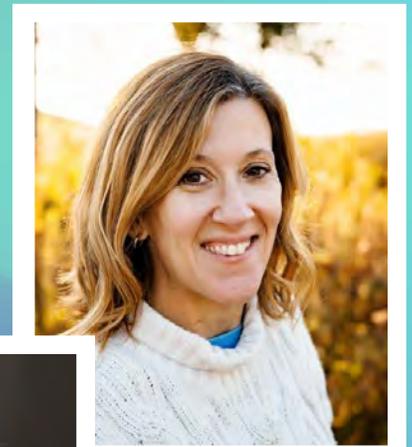
It is defined by community.

Together, you have shown what is possible when a community refuses to accept limits, when hope is paired with action, and compassion is matched with commitment. Because of you, the Angelman Syndrome Foundation continued to grow not just in size or reach, but in impact and purpose.

This year, your support fueled meaningful progress across every pillar of our mission. Families found connection, resources, and relief through expanded support programs. Clinics and clinicians were strengthened through our growing clinic network and shared standards of care. Researchers moved closer to answers through ASF-funded science, collaboration, and data-driven initiatives. And our collective voice—rooted in lived experience—continued to shape conversations around care, access, and the future of Angelman syndrome.

But beyond the milestones and metrics, what stands out most is how this work happened.

It happened because parents showed up for one another. Because donors trusted us with their generosity. Because scientists and clinicians partnered across institutions and borders.



AMANDA MOORE



LESLEY MCCULLOUGH MCCALLISTER

Because advocates spoke up when it mattered most.

It happened because this community believes deeply that individuals with Angelman syndrome deserve every

opportunity to live full, meaningful lives, and that families should never have to navigate this journey alone.

As leaders of this organization, and as parents and advocates ourselves, we are profoundly grateful. We see your dedication. We feel your trust. And we carry a deep responsibility to honor both through thoughtful stewardship, transparency, and relentless focus on impact.

The year ahead will bring new challenges and new opportunities, but if this year has taught us anything, it is that together, we are stronger than any obstacle.

Thank you for believing in this work.
Thank you for believing in each other.
Thank you for being the power behind our progress.

With gratitude and hope,
AMANDA MOORE
Chief Executive Officer
Angelman Syndrome Foundation

LESLEY MCCULLOUGH MCCALLISTER
President, Board of Directors
Angelman Syndrome Foundation



2025 MILESTONES



AS GROWS UP: EXPANDING SUPPORT FOR ADULTHOOD

AS Grows Up marked a significant step forward in supporting individuals with Angelman syndrome as they transition into adulthood. The initiative introduced new resources, including the ASF Provider Registry, Transition of Care Toolkit and Adult Housing Champions.

MOVEMENT DISORDERS RESEARCH EXPANDS UNDER DR. CARSON

ASF-supported research continued to advance understanding of movement disorders in Angelman syndrome, with Dr. Robert Carson and colleagues leading multi-site analysis to better characterize abnormal movements like dystonia, tremors, and myoclonus.

FIRST PATIENT DOSED IN PIVOTAL PHASE 3 STUDIES

In 2025, Ionis Pharmaceuticals and Ultragenyx each announced the dosing of their first participants in global Phase 3 clinical trials evaluating investigational therapies for the treatment of Angelman syndrome.

ASF LAUNCHES INTERNATIONAL ANGELMAN CLINIC NETWORK

A new partnership with the ASF Clinic at Erasmus MC in Rotterdam will strengthen access to specialized, coordinated care that families outside the US can rely on. The International ASF Clinic Network reinforces our commitment to global standards of care and expanding access to clinical trials worldwide.

NEW TOOL ADVANCES UNDERSTANDING OF UBE3A VARIANTS

ASF-supported research led by Dr. Mark Zylka advanced understanding of UBE3A variants through the development of a new research tool for Angelman syndrome. This work helps researchers better study how different UBE3A changes impact the condition, strengthening the foundation for future discoveries and therapeutic development.

ANGELMAN SYNDROME ADVOCACY ADVANCES ON CAPITOL HILL

In March 2025, Angelman syndrome advocates, in partnership with ASF & FAST, met with Congressional staff to advance key policy priorities, including caregiving legislation, protecting access to Medicaid, and securing research funding. Despite a challenging legislative year, all three Angelman syndrome-specific FY26 appropriations requests were recognized by Congress.

NIH AWARDS \$1.5M FOR ANGELMAN GENOME EDITING RESEARCH

In 2025, the National Institutes of Health awarded \$1.5 million to the University of North Carolina to advance a genome editor therapy for Angelman syndrome. This critical investment builds on ASF-funded research and was made possible by the continued support of ASF families, donors, and advocates.

ADULT TRANSITION TOOLKIT LAUNCHED

In 2025, ASF launched the Adult Transition Toolkit, equipping families and caregivers with practical guidance and resources to support the transition from pediatric to adult care and services.



FAMILY SUPPORT

Supporting Families Through Every Stage of the Angelman Journey

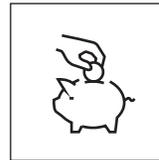
At the ASF, supporting families is at the heart of everything we do. From the moment of diagnosis through adulthood, ASF provides resources, programs, and connections that help individuals with Angelman syndrome and their families navigate each stage of life with confidence and care.

2025 FAMILY SUPPORT HIGHLIGHTS



AS GROWS UP PROGRAM

Launched to support adults with Angelman syndrome through the Adult Housing Champions and Adult Task Force.



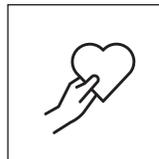
ASF FAMILY FUND

121 grants awarded, totaling **\$299,676** in direct family support



COUNSELING SERVICES

506 FREE COUNSELING SESSIONS provided to individuals and families affected by AS.



IEP CONSULT SERVICES

308 IEP CONSULT SESSIONS supporting educational advocacy.



PODCAST

16 EPISODES PUBLISHED, reaching **1,400 DOWNLOADS** across **72 COUNTRIES**.



RESEARCH

ASF-FUNDED RESEARCH HIGHLIGHTS

\$17.M+

Research Investment
Since 1996*

\$1.2M+

Research
Funded in 2025**



FY25 CLINICAL TRIALS

This year marked another important step forward for the Angelman syndrome community, with multiple clinical trials and observational studies advancing across a range of therapeutic and supportive approaches, reflecting growing scientific momentum. These included gene- and RNA-targeted therapies, antisense oligonucleotide (ASO) programs, small-molecule and pathway-modulating treatments, as well as natural history and outcome-measure studies designed to deepen understanding of Angelman syndrome and prepare the field for future therapies. Importantly, clinical trials were conducted in 18 Angelman Syndrome Foundation Clinic Network sites, underscoring the critical role ASF clinics play as trusted, experienced research centers. By integrating research into specialized clinical care, ASF clinics continue to support families who choose to participate in trials while ensuring studies are carried out thoughtfully, safely, and with deep expertise in Angelman syndrome.

To learn more about clinical trials visit: [Angelman.org/clinical-trials](https://www.angelman.org/clinical-trials)

* Cumulative research investment

** Total includes first- and second-year grants from current and / or prior year funding rounds. Full award amount is not fully expended during a fiscal year if the study is multi-years.



2025 RESEARCH PROJECTS SUPPORTED

UNC - CHAPEL HILL

Zylka: Development of Biosensor, Year 1

UNIVERSITY OF MASSACHUSETTS AMHERST

Streeter: Identification of a New UBE3A Target in Angelman Syndrome, Year 1

VANDERBILT UNIVERSITY MEDICAL CENTER (VUMC)

Carson: Multi-center Movement Disorder Research Study, Year 2

UNIVERSITY OF CONNECTICUT HEALTH CENTER

Levine: Hemizygous HERC2 Deletion Study, Year 2

NEW YORK UNIVERSITY

Margolis: Angelman Syndrome and the Gut, Year 2

UNIVERSITY OF CONNECTICUT HEALTH CENTER

Levine: Hemizygous HERC2 Deletion Study, Year 2

ANGELMAN SYNDROME OUTCOMES MEASURES AND BIOMARKERS CONSORTIUM

Natural History Study, Year 3 (in collaboration with Wen-Hann Tan, MD, and Boston Children's Hospital)

LADDER DATABASE

LADDER integrated 158 datasets from 16 sources into one secure, research-ready resource—including the full Angelman Natural History Study— creating unprecedented power to understand disease progression, identify meaningful outcomes, and accelerate research across the field.



angelman
SYNDROME FOUNDATION

Clinics

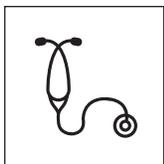
For Patients. For Providers. Together, Toward The Cure.



CONNECTING EXPERTISE. STRENGTHENING CARE. ADVANCING RESEARCH.

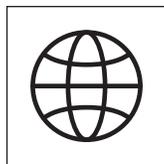
The ASF Clinics and the LADDER Learning Network connect expert clinicians, researchers, and families to improve care for individuals with Angelman syndrome. Through collaboration, shared data, and continuous learning across clinical sites, these programs support evidence-based care today while helping prepare the field for tomorrow's treatments.

2025 HIGHLIGHTS



1,552 PATIENTS

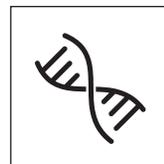
Patients Served at
ASF Clinics Worldwide



35 TOTAL
ASF Clinics



1,091 INDIVIDUALS
Enrolled in LADDER



2 NEW
ASF Clinics



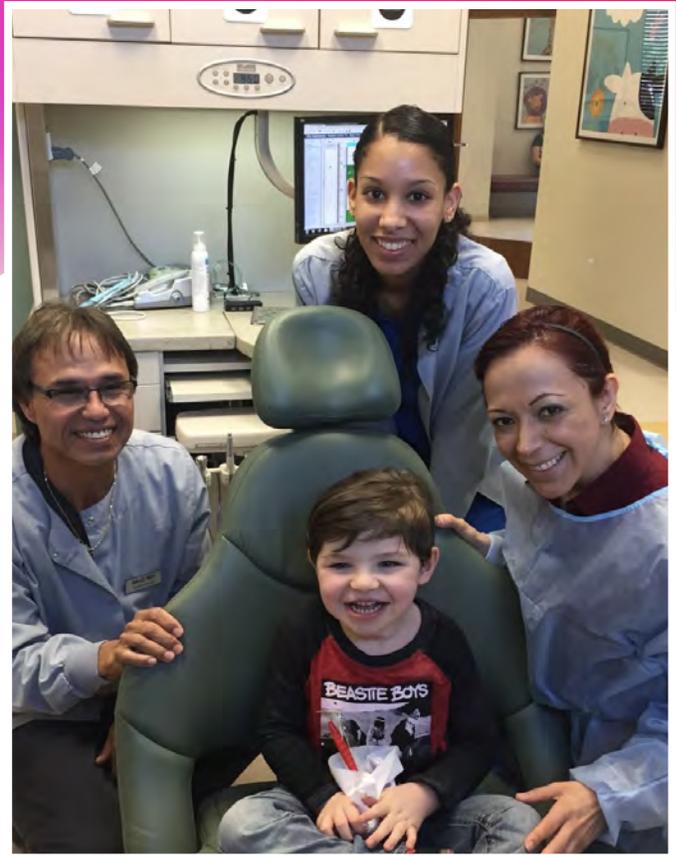


THE POWER OF ACCESS TO CARE

This year, the ASF Clinic Network demonstrated the power of community in action—serving **more than 3,000 individuals living with Angelman syndrome** across our growing network of expert clinics.

A new partnership with the ASF Clinic at Erasmus MC in Rotterdam will strengthen access to specialized, coordinated care that families outside the US can rely on. The **International ASF Clinic Network**, reinforces our commitment to global standards of care and expanding access to clinical trials worldwide.

Looking ahead to early 2026, we are excited to welcome new clinic sites—continuing to bring high-quality, Angelman-informed care closer to families everywhere.



THE POWER OF DATA

The LADDER Database represents the power of data working together to accelerate progress for the Angelman community. Created to break down long-standing data silos, LADDER brings **158 datasets from 16 sources** into one secure, research-ready platform—including the **full Angelman Natural History Study**—ensuring that decades of carefully collected information are preserved, connected, and actively used.

For families, this means that the time, trust, and effort invested in clinic visits, studies, and surveys continue to matter long after participation ends. Every data point helps tell a broader story and strengthens our understanding of Angelman syndrome across the lifespan.

For donors, LADDER maximizes philanthropic impact by making data more efficient, accessible, and meaningful to qualified researchers and industry partners—helping shorten the path from research to real-world treatments.



FUNDRAISERS

Across the country, families, friends, and supporters came together through community-led fundraising efforts to advance ASF's mission.



2025 ANGELMAN STRONG | *Raised +\$1,460,000*

In 2025, Angelman Strong brought the Angelman community together across the country to raise critical support for ASF's mission. With 45 events nationwide, including 2 5Ks, 6 community events, and 37 walks, a total of 9,419 participants united in shared purpose, raising over \$1,460,000 to support research, clinical care, and family programs. Angelman Strong is an expression of community, connection, and collective impact for individuals and families affected by Angelman syndrome.

2024 CHICAGO MARATHON | WINDY CITY ANGELS | *Raised +\$187,900*

The Windy City Angels took on the 2024 Chicago Marathon in support of the Angelman community, uniting 47 runners alongside four duo teams in a powerful show of determination and teamwork. Together, the team raised over \$187,900, turning every mile into meaningful support for ASF's research, clinical care, and family support programs.



END-OF-YEAR CAMPAIGN | POWER OF YOU | *Raised \$1.175M*

ASF's Power of You campaign celebrated the collective impact of individual generosity across the Angelman community. Together, families, donors, and advocates raised \$1.175 million, supporting ASF's work in research, clinical care, and family programs. The campaign reinforced a simple truth: every contribution helps move progress forward for individuals and families affected by Angelman syndrome.



COMMUNITY FUNDRAISERS

Throughout the year, families, friends, and supporters hosted community-led fundraisers to advance ASF's mission. Below are just some of the many events that helped strengthen the Angelman community and support research, care, and family programs.

Below are just some of the many fundraisers that took place in 2025.

Chip Away at AS Golf Tournament
Raised \$9,000

Multiple Cornhole Tournaments
Raised \$28,237

2025 Disney Marathon
Raised \$9,245

Golf Outing for Logan
Raised \$14,110

Sutton Smith Golf
Raised \$15,000

Ragnar Relay
Raised \$24,050

The Granville Angels
Raised \$10,900

The Hope Classic
Raised \$8,815

Go Gus Go Golf Outing
Raised \$12,000

Jack's Tap Golf Outing for Logan
Raised \$14,000

GM Car Show
Raised \$7,126

Bowling Tournament
Raised \$7,500



BOARD, COMMITTEE & ADVISORY MEMBERS

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THANK YOU TO OUR VISIONARY LEADERS

Donations received October 2024 to September 2025.

Betty J. Shaw Benefactors, \$100,000+

Ionis Pharmaceuticals, Renee Pritzker

Harry Angelman Champions, \$50,000+

Anonymous, Maddie's Mission Foundation, Oak Hill Bio Ltd, Ultragenyx Pharmaceutical, Inc.

Heroes Giving Hope, \$10,000+

Anonymous, Andres Arango, Antonieta Arango, Javier Arango, Tracy and John Atkinson, John and Cathrine M. Blain, Blarney For Angelman Foundation, Child Neurology Foundation, Nicholas and Allie Cox, Colin and Regina Fechter, Kurt Fenzan, Genentech Inc, Gloria Gibson, Jay and Amy Granzow, Gina M. Hartley, Jack's, Ruth Jurgensmeyer, John and Kelsey Laskowski, Keith F. Lauder, Lennar Foundation, Inc., James and Ana Libby, MassMutual SpecialCare, Maverick Capital Foundation, Lesley and Andrew McCallister, Timothy and Gretchen McCarty, Tom and Ruthann McCarty, Keith and Elise McDonald, Patrick McKenna, Richard and Alyssa Newton, Christian and Anna Pache, Christine Palmer, Steven and Mia Piluso, Wayne and Jana Pott, Sarah N. Pritzker, Rakoczy Molino Mazzochi Siwik LLP, William A. Rakoczy, Ron and Mary Pott Family Foundation, Bryan Schnick and Allyson Tole, Alexander and Sierra Smith, Melissa and Adam Stone, The Granville Angels Foundation, The Melanie Foundation, William and Joyce Veldman, Victor and Clara C. Battin Foundation

Sustainer, \$5,000+

Anonymous, John and Christine Bakalar, Alexa Barnett, Arthur and Marjorie Beaudet, Blue Star Marine LA, Jana Carlson, Clint W. Perryman, P.C., Nancy Rae Cohen, Crestwood High School, EQT Corporation DAF, EveryLife Foundation for Rare Diseases, Michelle and Jude Fontenot, Friends of James, Inc., Brian Graves, Jeanne and Bruce Graves, Merewyn and Alan Harrington, Rachel Hartberg and Emanuel Huerta-Gutierrez, Dan and Karen Harvey, Doug and Lindsey Hene, Bonnie and Dennis Knoedler, Michael and Emily Leighton, Paul Molino, Amanda and Adam Moore, Greg and Sylvia Moore, MSA Design, John R. Niepold, Jane O'Leary and Jonathan Ruckdeschel, Denise Olsen, Thomas and Leann O'Rourke, Douglas and Angela Patterson, John and Mary Pipal, Deirdre and Mark Rajkowski, Terence Rooney, David and Jenny Routh, Leah and Bobby Scott, Robert Sederman, Sue and Bryan Stahmer, John Sugden and Ana Monaldi, Texas Children's Hospital, The Clarke Charitable Foundation, The Hometown Foundation, Inc., Robert and Kelly Van Der Vaart, W.Y. Campbell Family Foundation, Mary Wagstaff

*in memoriam



FINANCIAL BREAKDOWN

STATEMENT OF FINANCIAL POSITION FOR THE YEAR ENDED SEPTEMBER 30, 2024 AND 2023

| Current Assets: | 2025 | 2024 |
|--|--------------------|--------------------|
| Cash and Cash Equivalents | \$912,921 | \$1,122,681 |
| Pledges Receivable, Current Portion | \$10,000 | \$15,518 |
| Investments | \$1,465,718 | \$1,391,676 |
| Inventory | \$129,594 | \$6,813 |
| Pre-paid Expenses | \$70,998 | \$93,142 |
| Total Current Assets | \$2,589,231 | \$2,629,830 |
| Property & Equipment (at cost): | 2025 | 2024 |
| Office Furniture, Fixtures and Equipment | \$2,921 | \$2,921 |
| Computer Hardware | \$19,172 | \$19,172 |
| Software | \$533,285 | \$533,285 |
| Website | \$62,250 | \$24,000 |
| Less - Accumulated Depreciation | \$(579,202) | \$(575,568) |
| NET Property & Equipment | \$38,426 | \$3,810 |
| Other Assets: | 2025 | 2024 |
| Pledges receivable, long-term portion, net of allowance of \$10,000 and \$0 at September 30, 2025 and 2024, respectively | \$9,639 | \$20,000 |
| TOTAL ASSETS | \$2,637,296 | \$2,653,640 |
| Liabilities & Net Assets | 2025 | 2024 |
| Current Liabilities | | |
| Accounts Payable | \$17,684 | \$98,619 |
| Grants Payable | \$437,097 | \$563,922 |
| Accrued Payroll Expenses | \$70,618 | \$74,829 |
| Deferred Event Revenue | \$10,000 | - |
| Total Current Liabilities | \$535,399 | \$737,370 |
| Net Assets | 2025 | 2024 |
| Without Donor Restrictions | \$1,303,965 | \$1,074,253 |
| With Donor Restrictions | \$797,932 | \$842,017 |
| Total Net Assets | \$2,101,897 | \$1,916,270 |
| TOTAL LIABILITIES & NET ASSETS | \$2,637,296 | \$2,653,640 |

STATEMENT OF ACTIVITIES FOR THE YEAR ENDED SEPTEMBER 30, 2025 AND 2024

| PUBLIC SUPPORT & REVENUE | | |
|--|--------------------|--------------------|
| | 2025 | 2024 |
| Contributions | \$2,086,954 | \$1,601,206 |
| In-kind contributions | \$231,296 | \$12,128 |
| Biennial Conference | \$26,310 | \$212,824 |
| Special events, net of related expenses of \$205,404 and \$453,530, which includes in-kind revenue of \$152,269 and \$169,740 for 2025 and 2024, respectively | \$1,413,888 | \$1,701,796 |
| Net Investment Return (Loss) | \$130,984 | \$330,532 |
| Other Income | \$17,460 | \$5,123 |
| Net assets released from restrictions - satisfaction of program restrictions | ---- | ---- |
| TOTAL PUBLIC SUPPORT & REVENUE | \$3,906,892 | \$3,863,609 |
| FUNCTIONAL EXPENSES | | |
| Program Services | 2025 | 2024 |
| Family Support | \$1,419,474 | \$1,218,228 |
| Research | \$1,316,602 | \$1,334,111 |
| Biennial Conference & Symposium | \$91,968 | \$487,769 |
| TOTAL PROGRAM SERVICES | \$2,828,044 | \$3,040,108 |
| Management & General | \$304,815 | \$252,761 |
| Fundraising | \$588,406 | \$641,341 |
| TOTAL FUNCTIONAL EXPENSES | \$3,721,265 | \$3,934,210 |
| CHANGE IN NET ASSETS | | |
| | 2025 | 2024 |
| Change In Net Assets | \$185,627 | \$(70,601) |
| Net Assets, <i>Beginning Of Year</i> | \$1,916,270 | \$1,986,871 |
| Net Assets, <i>End Of Year</i> | \$2,101,897 | \$1,916,270 |



WHAT'S AHEAD

ASF looks ahead to another year of connection, progress, and community, bringing families, researchers, and supporters together to move our mission forward.

ANGELMAN STRONG 2026

May 2026*

Angelman Strong returns across the country with walks, runs, and community events uniting families and supporters in support of Angelman syndrome. Find your location at [Angelman.org/Strong](https://www.angelman.org/Strong).

**Date varies by location*

2026 ASF FAMILY CONFERENCE & RESEARCH SYMPOSIUM

Gaylord Rockies Resort & Convention Center, Aurora, CO

Research Symposium: July 29 – 30, 2026

Family Conference: July 30 – Aug 1, 2026

Families, clinicians, researchers, and advocates will gather for education, connection, and collaboration, bringing together the Angelman community and the latest research in one shared space. Register at [ASFConference.org](https://www.asfconference.org).

2026 CHICAGO MARATHON | WINDY CITY ANGELS

October 11, 2026

The Windy City Angels will once again take on the Chicago Marathon, turning every mile into meaningful support for individuals and families affected by Angelman syndrome. Support the team at [Angelman.org/Events/Chicago-Marathon-2026](https://www.angelman.org/Events/Chicago-Marathon-2026).



The mission of the Angelman Syndrome Foundation is to advance the awareness and treatment of Angelman syndrome through education and information, research and support for individuals with Angelman syndrome, their families and other concerned parties. We exist to give all of them a reason to smile, with the ultimate goal of finding a cure.

Join Our Community

